

106TH CONGRESS  
1ST SESSION

# H. R. 3301

To amend the Public Health Service Act with respect to children’s health.

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## IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 10, 1999

Mr. BILIRAKIS (for himself, Mr. BROWN of Ohio, Mrs. EMERSON, Mr. TOWNS, Mr. GREENWOOD, Mr. UPTON, Ms. DEGETTE, Mr. SMITH of New Jersey, Mr. WAXMAN, and Mr. WALSH) introduced the following bill; which was referred to the Committee on Commerce

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## A BILL

To amend the Public Health Service Act with respect to children’s health.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       This Act may be cited as the “Children’s Health Re-  
5       search and Prevention Amendments of 1999”.

6       **SEC. 2. TABLE OF CONTENTS.**

7       The table of contents for this Act is as follows:

Sec. 1. Short title.

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- Sec. 212. Developmental disabilities surveillance and research programs.
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#### CHAPTER 2—EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVI- TIES OF DEPARTMENT OF HEALTH AND HUMAN SERVICES WITH RESPECT TO AUTISM

- Sec. 218. Short title.
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Sec. 252. Establishment.

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and local grants for seizure disorder demonstration projects in  
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1           **TITLE I—REVISION AND**  
 2           **EXTENSION OF PROGRAMS**  
 3           **Subtitle A—Pediatric Research**  
 4           **Initiative**

5   **SEC. 101. SHORT TITLE.**

6           This subtitle may be cited as the “Pediatric Research  
 7 Initiative Act of 1999”.

8   **SEC. 102. ESTABLISHMENT OF A PEDIATRIC RESEARCH INI-**  
 9           **TIATIVE.**

10          Part A of title IV of the Public Health Service Act  
 11 (42 U.S.C. 281 et seq.) is amended by adding at the end  
 12 the following:

13   **“SEC. 404F. PEDIATRIC RESEARCH INITIATIVE.**

14          “(a) ESTABLISHMENT.—The Secretary shall estab-  
 15 lish within the Office of the Director of NIH a Pediatric  
 16 Research Initiative (referred to in this section as the ‘Ini-  
 17 tiative’). The Initiative shall be headed by the Director  
 18 of NIH.

19          “(b) PURPOSE.—The purpose of the Initiative is to  
 20 provide funds to enable the Director of NIH to  
 21 encourage—

1           “(1) increased support for pediatric biomedical  
2       research within the National Institutes of Health to  
3       ensure that the expanding opportunities for advance-  
4       ment in scientific investigations and care for chil-  
5       dren are realized;

6           “(2) enhanced collaborative efforts among the  
7       Institutes to support multidisciplinary research in  
8       the areas that the Director deems most promising;  
9       and

10          “(3) the development of adequate pediatric clin-  
11       ical trials and pediatric use information to promote  
12       the safer and more effective use of prescription  
13       drugs in the pediatric population.

14          “(c) DUTIES.—In carrying out subsection (b), the Di-  
15       rector of NIH shall—

16          “(1) consult with the Institute of Child Health  
17       and Human Development and the other Institutes,  
18       in considering their requests for new or expanded  
19       pediatric research efforts, and consult with other ad-  
20       visors as the Director determines appropriate;

21          “(2) have broad discretion in the allocation of  
22       any Initiative assistance among the Institutes,  
23       among types of grants, and between basic and clin-  
24       ical research so long as the—

1                   “(A) assistance is directly related to the ill-  
2                   nesses and conditions of children; and

3                   “(B) assistance is extramural in nature;  
4                   and

5                   “(3) be responsible for the oversight of any  
6                   newly appropriated Initiative funds and annually re-  
7                   port to Congress and the public on the extent of the  
8                   total extramural support for pediatric research  
9                   across the NIH, including the specific support and  
10                  research awards allocated through the Initiative.

11                  “(d) AUTHORIZATION.—For the purpose of carrying  
12                  out this section, there are authorized to be appropriated  
13                  such sums as may be necessary for each of the fiscal years  
14                  2000 through 2003.

15                  “(e) TRANSFER OF FUNDS.—The Director of NIH  
16                  may transfer amounts appropriated under this section to  
17                  any of the Institutes for a fiscal year to carry out the pur-  
18                  poses of the Initiative under this section.”.

19       **SEC. 103. INVESTMENT IN TOMORROW’S PEDIATRIC**  
20                               **RESEARCHERS.**

21                  Subpart 7 of part C of title IV of the Public Health  
22                  Service Act (42 U.S.C. 285g et seq.) is amended by adding  
23                  at the end the following:

1 **“SEC. 452E. INVESTMENT IN TOMORROW’S PEDIATRIC**  
 2 **RESEARCHERS.**

3 “(a) IN GENERAL.—The Secretary shall make avail-  
 4 able within the National Institute of Child Health and  
 5 Human Development enhanced support for extramural ac-  
 6 tivities relating to the training and career development of  
 7 pediatric researchers.

8 “(b) PURPOSE.—The purpose of support provided  
 9 under subsection (a) shall be to ensure the future supply  
 10 of researchers dedicated to the care and research needs  
 11 of children by providing for—

12 “(1) an increase in the number and size of in-  
 13 stitutional training grants to medical school pedi-  
 14 atric departments and children’s hospitals; and

15 “(2) an increase in the number of career devel-  
 16 opment awards for pediatricians building careers in  
 17 pediatric basic and clinical research.

18 “(c) AUTHORIZATION.—For the purpose of carrying  
 19 out this section, there are authorized to be appropriated  
 20 such sums as may be necessary for each of the fiscal years  
 21 2000 through 2003.”.

22 **Subtitle B—Other Programs**

23 **SEC. 111. CHILDHOOD IMMUNIZATIONS.**

24 Section 317(j)(1) of the Public Health Service Act  
 25 (42 U.S.C. 247b(j)(1)) is amended in the first sentence

1 by striking “1998” and all that follows and inserting  
2 “1998 through 2003.”.

3 **SEC. 112. SCREENINGS, REFERRALS, AND EDUCATION**  
4 **REGARDING LEAD POISONING.**

5 Section 317A(l)(1) of the Public Health Service Act  
6 (42 U.S.C. 247b–1(l)(1)) is amended by striking “1994”  
7 and all that follows and inserting “1994 through 2003.”.

8 **SEC. 113. PREVENTION AND CONTROL OF INJURIES; TRAUMATIC**  
9 **BRAIN INJURY.**

10 Section 394A of the Public Health Service Act (42  
11 U.S.C. 280b–3) is amended by striking “and” after  
12 “1994” and by inserting before the period the following:  
13 “, and such sums as may be necessary for each of the  
14 fiscal years 2000 through 2003.”.

15 **TITLE II—CHILDREN’S HEALTH**  
16 **RESEARCH AND PREVENTION**  
17 **ACTIVITIES**

18 **Subtitle A—Early Detection, Diag-**  
19 **nosis, and Treatment Regarding**  
20 **Hearing Loss in Infants**

21 **SEC. 201. SHORT TITLE.**

22 This subtitle may be cited as the “Newborn and In-  
23 fant Hearing Screening and Intervention Act of 1999”.



1 **SEC. 202. EARLY DETECTION, DIAGNOSIS, AND INTERVEN-**  
2 **TIONS FOR NEWBORNS AND INFANTS WITH**  
3 **HEARING LOSS.**

4 (a) DEFINITIONS.—For the purposes of this subtitle  
5 only, the following terms in this section are defined as fol-  
6 lows:

7 (1) HEARING SCREENING.—Newborn and in-  
8 fant hearing screening consists of objective physio-  
9 logic procedures to detect possible hearing loss and  
10 to identify newborns and infants who, after re-  
11 screening, require further audiologic and medical  
12 evaluations.

13 (2) AUDIOLOGIC EVALUATION.—Audiologic  
14 evaluation consists of procedures to assess the status  
15 of the auditory system; to establish the site of the  
16 auditory disorder; the type and degree of hearing  
17 loss, and the potential effects of hearing loss on  
18 communication; and to identify appropriate treat-  
19 ment and referral options. Referral options should  
20 include linkage to state IDEA Part C coordinating  
21 agencies or other appropriate agencies, medical eval-  
22 uation, hearing aid/sensory aid assessment,  
23 audiologic rehabilitation treatment, national and  
24 local consumer, self-help, parent, and education or-  
25 ganizations, and other family-centered services.

1           (3) MEDICAL EVALUATION.—Medical evaluation  
2       by a physician consists of key components including  
3       history, examination, and medical decision making  
4       focused on symptomatic and related body systems  
5       for the purpose of diagnosing the etiology of hearing  
6       loss and related physical conditions, and for identi-  
7       fying appropriate treatment and referral options.

8           (4) MEDICAL INTERVENTION.—Medical inter-  
9       vention is the process by which a physician provides  
10      medical diagnosis and direction for medical and/or  
11      surgical treatment options of hearing loss and/or re-  
12      lated medical disorder associated with hearing loss.

13          (5) AUDIOLOGIC REHABILITATION.—Audiologic  
14      rehabilitation (intervention) consists of procedures,  
15      techniques, and technologies to facilitate the recep-  
16      tive and expressive communication abilities of a child  
17      with hearing loss.

18          (6) EARLY INTERVENTION.—Early intervention  
19      (e.g., nonmedical) means providing appropriate serv-  
20      ices for the child with hearing loss and ensuring that  
21      families of the child are provided comprehensive,  
22      consumer-oriented information about the full range  
23      of family support, training, information services,  
24      communication options and are given the oppor-

1 tunity to consider the full range of educational and  
2 program placements and options for their child.

3 (b) PURPOSES.—The purposes of this subtitle are to  
4 clarify the authority within the Public Health Service Act  
5 to authorize statewide newborn and infant hearing screen-  
6 ing, evaluation and intervention programs and systems,  
7 technical assistance, a national applied research program,  
8 and interagency and private sector collaboration for policy  
9 development, in order to assist the States in making  
10 progress toward the following goals:

11 (1) All babies born in hospitals in the United  
12 States and its territories should have a hearing  
13 screening before leaving the birthing facility. Babies  
14 born in other countries and residing in the United  
15 States via immigration or adoption should have a  
16 hearing screening as early as possible.

17 (2) All babies who are not born in hospitals in  
18 the United States and its territories should have a  
19 hearing screening within the first 3 months of life.

20 (3) Appropriate audiologic and medical evalua-  
21 tions should be conducted by 3 months for all  
22 newborns and infants suspected of having hearing  
23 loss to allow appropriate referral and provisions for  
24 audiologic rehabilitation, medical and early interven-  
25 tion before the age of 6 months.

1           (4) All newborn and infant hearing screening  
2       programs and systems should include a component  
3       for audiologic rehabilitation, medical and early inter-  
4       vention options that ensures linkage to any new and  
5       existing state-wide systems of intervention and reha-  
6       bilitative services for newborns and infants with  
7       hearing loss.

8           (5) Public policy in regard to newborn and in-  
9       fant hearing screening and intervention should be  
10      based on applied research and the recognition that  
11      newborns, infants, toddlers, and children who are  
12      deaf or hard-of-hearing have unique language, learn-  
13      ing, and communication needs, and should be the re-  
14      sult of consultation with pertinent public and private  
15      sectors.

16      (c) STATEWIDE NEWBORN AND INFANT HEARING  
17      SCREENING, EVALUATION AND INTERVENTION PRO-  
18      GRAMS AND SYSTEMS.—The Secretary of Health and  
19      Human Services (in this subtitle referred to as the “Sec-  
20      retary”), acting through the Administrator of the Health  
21      Resources and Services Administration, shall make awards  
22      of grants or cooperative agreements to develop statewide  
23      newborn and infant hearing screening, evaluation and  
24      intervention programs and systems for the following pur-  
25      poses:

1           (1) To develop and monitor the efficacy of  
2       state-wide newborn and infant hearing screening,  
3       evaluation and intervention programs and systems.  
4       Early intervention includes referral to schools and  
5       agencies, including community, consumer, and par-  
6       ent-based agencies and organizations and other pro-  
7       grams mandated by Part C of the Individuals with  
8       Disabilities Education Act, which offer programs  
9       specifically designed to meet the unique language  
10      and communication needs of deaf and hard of hear-  
11      ing newborns, infants, toddlers, and children.

12           (2) To collect data on statewide newborn and  
13      infant hearing screening, evaluation and intervention  
14      programs and systems that can be used for applied  
15      research, program evaluation and policy develop-  
16      ment.

17      (d) TECHNICAL ASSISTANCE, DATA MANAGEMENT,  
18      AND APPLIED RESEARCH.—

19           (1) CENTERS FOR DISEASE CONTROL AND PRE-  
20      VENTION.—The Secretary, acting through the Direc-  
21      tor of the Centers for Disease Control and Preven-  
22      tion, shall make awards of grants or cooperative  
23      agreements to provide technical assistance to State  
24      agencies to complement an intramural program and  
25      to conduct applied research related to newborn and

1 infant hearing screening, evaluation and intervention  
2 programs and systems. The program shall develop  
3 standardized procedures for data management and  
4 program effectiveness and costs, such as—

5 (A) to ensure quality monitoring of new-  
6 born and infant hearing loss screening, evalua-  
7 tion, and intervention programs and systems;

8 (B) to provide technical assistance on data  
9 collection and management;

10 (C) to study the costs and effectiveness of  
11 newborn and infant hearing screening, evalua-  
12 tion and intervention programs and systems  
13 conducted by State-based programs in order to  
14 answer issues of importance to state and na-  
15 tional policymakers;

16 (D) to identify the causes and risk factors  
17 for congenital hearing loss;

18 (E) to study the effectiveness of newborn  
19 and infant hearing screening, audiologic and  
20 medical evaluations and intervention programs  
21 and systems by assessing the health, intellectual  
22 and social developmental, cognitive, and lan-  
23 guage status of these children at school age;  
24 and

1 (F) to promote the sharing of data regard-  
2 ing early hearing loss with state-based birth de-  
3 fects and developmental disabilities monitoring  
4 programs for the purpose of identifying pre-  
5 viously unknown causes of hearing loss.

6 (2) NATIONAL INSTITUTES OF HEALTH.—The  
7 Director of the National Institutes of Health, acting  
8 through the Director of the National Institute on  
9 Deafness and Other Communication Disorders, shall  
10 for purposes of this section, continue a program of  
11 research and development on the efficacy of new  
12 screening techniques and technology, including clin-  
13 ical studies of screening methods, studies on efficacy  
14 of intervention, and related research.

15 (e) COORDINATION AND COLLABORATION.—

16 (1) IN GENERAL.—In carrying out programs  
17 under this section, the Administrator of the Health  
18 Resources and Services Administration, the Director  
19 of the Centers for Disease Control and Prevention,  
20 and the Director of the National Institutes of Health  
21 shall collaborate and consult with other Federal  
22 agencies; State and local agencies, including those  
23 responsible for early intervention services pursuant  
24 to Title XIX of the Social Security Act (Medicaid  
25 Early and Periodic Screening, Diagnosis and Treat-

1       ment Program); Title XXI of the Social Security Act  
2       (State Children’s Health Insurance Program); Title  
3       V of the Social Security Act (Maternal and Child  
4       Health Block Grant Program; and Part C of the In-  
5       dividuals with Disabilities Education Act); consumer  
6       groups of and that serve individuals who are deaf  
7       and hard-of-hearing and their families; appropriate  
8       national medical and other health and education spe-  
9       cialty organizations; persons who are deaf and hard-  
10      of-hearing and their families; other qualified profes-  
11      sional personnel who are proficient in deaf or hard-  
12      of-hearing children’s language and who possess the  
13      specialized knowledge, skills, and attributes needed  
14      to serve deaf and hard-of-hearing newborns, infants,  
15      toddlers, children, and their families; third-party  
16      payers and managed care organizations; and related  
17      commercial industries.

18           (2) POLICY DEVELOPMENT.—The Adminis-  
19      trator of the Health Resources and Services Admin-  
20      istration, the Director of the Centers for Disease  
21      Control and Prevention, and the Director of the Na-  
22      tional Institutes of Health shall coordinate and col-  
23      laborate on recommendations for policy development  
24      at the Federal and state levels and with the private  
25      sector, including consumer, medical and other health



1 and education professional-based organizations, with  
2 respect to newborn and infant hearing screening,  
3 evaluation and intervention programs and systems.

4 (3) STATE EARLY DETECTION, DIAGNOSIS, AND  
5 INTERVENTION PROGRAMS AND SYSTEMS; DATA COL-  
6 LECTION.—The Administrator of the Health Re-  
7 sources and Services Administration and the Direc-  
8 tor of the Centers for Disease Control and Preven-  
9 tion shall coordinate and collaborate in assisting  
10 States to establish newborn and infant hearing  
11 screening, evaluation and intervention programs and  
12 systems under subsection (c) and to develop a data  
13 collection system under subsection (d).

14 (f) RULE OF CONSTRUCTION.—Nothing in this sub-  
15 title shall be construed to preempt any State law.

16 (g) AUTHORIZATION OF APPROPRIATIONS.—

17 (1) STATEWIDE NEWBORN AND INFANT HEAR-  
18 ING SCREENING, EVALUATION AND INTERVENTION  
19 PROGRAMS AND SYSTEMS.—For the purpose of car-  
20 rying out subsection (c), there are authorized to be  
21 appropriated to the Health Resources and Services  
22 Administration such sums as may be necessary for  
23 each of the fiscal years 2000 through 2003.

24 (2) TECHNICAL ASSISTANCE, DATA MANAGE-  
25 MENT, AND APPLIED RESEARCH; CENTERS FOR DIS-

1 EASE CONTROL AND PREVENTION.—For the purpose  
 2 of carrying out subsection (d)(1), there are author-  
 3 ized to be appropriated to the Centers for Disease  
 4 Control and Prevention such sums as may be nec-  
 5 essary for each of the fiscal years 2000 through  
 6 2003.

7 (3) TECHNICAL ASSISTANCE, DATA MANAGE-  
 8 MENT, AND APPLIED RESEARCH; NATIONAL INSTI-  
 9 TUTE ON DEAFNESS AND OTHER COMMUNICATION  
 10 DISORDERS.—For the purpose of carrying out sub-  
 11 section (d)(2), there are authorized to be appro-  
 12 priated to the National Institute on Deafness and  
 13 Other Communication Disorders such sums as may  
 14 be necessary for each of the fiscal years 2000  
 15 through 2003.

## 16 **Subtitle B—Autism**

### 17 **CHAPTER 1—SURVEILLANCE AND RE-** 18 **SEARCH REGARDING PREVALENCE** 19 **AND PATTERN OF AUTISM**

#### 20 **SEC. 211. SHORT TITLE.**

21 This chapter may be cited as the “Autism Statistics,  
 22 Surveillance, Research, and Epidemiology Act of 1999  
 23 (ASSURE)”.

1 **SEC. 212. DEVELOPMENTAL DISABILITIES SURVEILLANCE**  
2 **AND RESEARCH PROGRAMS.**

3 (a) NATIONAL AUTISM AND PERVASIVE DEVELOP-  
4 MENTAL DISABILITIES SURVEILLANCE PROGRAM.—The  
5 Secretary of Health and Human Services (in this chapter  
6 referred to as the “Secretary”), acting through the Direc-  
7 tor of the Centers for Disease Control and Prevention,  
8 may make awards of grants and cooperative agreements  
9 for the collection, analysis, and reporting of data on au-  
10 tism and pervasive developmental disabilities. An entity  
11 may receive such an award only if the entity is a public  
12 or nonprofit private entity (including health departments  
13 of States and political subdivisions of States, and includ-  
14 ing universities and other educational entities). In making  
15 such awards, the Secretary may provide direct technical  
16 assistance in lieu of cash.

17 (b) CENTERS OF EXCELLENCE IN AUTISM AND PER-  
18 VASIVE DEVELOPMENTAL DISABILITIES EPIDEMI-  
19 OLOGY.—

20 (1) IN GENERAL.—The Secretary, acting  
21 through the Director of the Centers for Disease  
22 Control and Prevention, shall (subject to the extent  
23 of amounts made available in appropriations Acts)  
24 establish not less than three, and not more than five,  
25 regional centers of excellence in autism and perva-  
26 sive developmental disabilities epidemiology for the

1 purpose of collecting and analyzing information on  
2 the number, incidence, correlates, and causes of au-  
3 tism and related developmental disabilities.

4 (2) RECIPIENTS OF AWARDS FOR ESTABLISH-  
5 MENT OF CENTERS.—Centers under paragraph (1)  
6 shall be established and operated through the award  
7 of grants or cooperative agreements to public or  
8 nonprofit private entities that conduct research, in-  
9 cluding health departments of States and political  
10 subdivisions of States, and including universities and  
11 other educational entities.

12 (3) CERTAIN REQUIREMENTS.—An award for a  
13 center under paragraph (1) may be made only if the  
14 entity involved submits to the Secretary an applica-  
15 tion containing such agreements and information as  
16 the Secretary may require, including an agreement  
17 that the center involved will operate in accordance  
18 with the following:

19 (A) The center will collect, analyze, and re-  
20 port autism and pervasive developmental dis-  
21 abilities data according to guidelines prescribed  
22 by the Director, after consultation with relevant  
23 State and local public health officials, private  
24 sector developmental disability researchers, and

1 advocates for those with developmental disabil-  
2 ities;

3 (B) The center will assist with the develop-  
4 ment and coordination of State autism and per-  
5 vasive developmental disabilities surveillance ef-  
6 forts within a region;

7 (C) The center will provide education,  
8 training, and clinical skills improvement for  
9 health professionals aimed at better under-  
10 standing and treatment of autism and related  
11 developmental disabilities; and

12 (D) The center will identify eligible cases  
13 and controls through its surveillance systems  
14 and conduct research into factors which may  
15 cause autism and related developmental disabil-  
16 ities; each program will develop or extend an  
17 area of special research expertise (including,  
18 but not limited to, genetics, environmental ex-  
19 posure to contaminants, immunology, and other  
20 relevant research specialty areas).

21 **SEC. 213. CLEARINGHOUSE.**

22 The Secretary, acting through the Director of the  
23 Centers for Disease Control and Prevention, shall carry  
24 out the following:

1           (1) The Centers for Disease Control and Pre-  
2           vention shall serve as the coordinating agency for  
3           autism and pervasive developmental disabilities sur-  
4           veillance activities through the establishment of a  
5           clearinghouse for the collection and storage of data  
6           generated from the monitoring programs created by  
7           this chapter. The functions of such a clearinghouse  
8           shall include facilitating the coordination of research  
9           and policy development relating to the epidemiology  
10          of autism and other pervasive developmental disabil-  
11          ities.

12          (2) The Secretary, acting through the Centers  
13          for Disease Control and Prevention, shall coordinate  
14          the Federal response to requests for assistance from  
15          State health department officials regarding potential  
16          or alleged autism or developmental disability clus-  
17          ters.

18 **SEC. 214. ADVISORY COMMITTEE.**

19          (a) IN GENERAL.—The Secretary shall establish an  
20          Advisory Committee for Autism and Pervasive Develop-  
21          mental Disabilities Epidemiology Research (in this section  
22          referred to as the “Committee”). The Committee shall  
23          provide advice and recommendations to the Director of the  
24          Centers for Disease Control and Prevention on—

1           (1) the establishment of a national autism and  
2           pervasive developmental disabilities surveillance pro-  
3           gram;

4           (2) the establishment of centers of excellence in  
5           autism and pervasive developmental disabilities epi-  
6           demiology;

7           (3) methods and procedures to more effectively  
8           coordinate government and non-government pro-  
9           grams and research on autism and pervasive devel-  
10          opmental disabilities epidemiology; and

11          (4) the effective operation of autism and perva-  
12          sive developmental disabilities epidemiology research  
13          activities.

14          (b) COMPOSITION.—

15           (1) IN GENERAL.—The Committee shall be  
16           composed of ex officio members in accordance with  
17           paragraph (2) and 11 appointed members in accord-  
18           ance with paragraph (3).

19           (2) EX OFFICIO MEMBERS.—The following offi-  
20           cials shall serve as ex officio members of the Com-  
21           mittee:

22                   (A) The Director of the National Center  
23                   for Environmental Health.

1 (B) The Assistant Administrator of the  
2 Agency for Toxic Substances and Disease Reg-  
3 istry.

4 (C) The Director of the National Institute  
5 of Child Health and Human Development.

6 (D) The Director of the National Institute  
7 of Neurological Disorders and Stroke.

8 (3) APPOINTED MEMBERS.—Appointments to  
9 the Committee shall be made in accordance with the  
10 following:

11 (A) Two members shall be research sci-  
12 entists with demonstrated achievements in re-  
13 search related to autism and related develop-  
14 mental disabilities. The scientists shall be ap-  
15 pointed by the Secretary in consultation with  
16 the National Academy of Sciences.

17 (B) Five members shall be representatives  
18 of the five national organizations whose primary  
19 emphasis is on research into autism and other  
20 pervasive developmental disabilities. One rep-  
21 resentative from each of such organizations  
22 shall be appointed by the Secretary in consulta-  
23 tion with the National Academy of Sciences.

24 (C) Two members shall be clinicians whose  
25 practice is primarily devoted to the treatment of



1 individuals with autism and other pervasive de-  
2 velopmental disabilities. The clinicians shall be  
3 appointed by the Secretary in consultation with  
4 the Institute of Medicine and the National  
5 Academy of Sciences.

6 (D) Two members shall be individuals who  
7 are the parents or legal guardians of a person  
8 or persons with autism or other pervasive devel-  
9 opmental disabilities. The individuals shall be  
10 appointed by the Secretary in consultation with  
11 the ex officio members under paragraph (1) and  
12 the five national organizations referred to in  
13 subparagraph (B).

14 (c) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;  
15 OTHER PROVISIONS.—The following apply with respect to  
16 the Committee:

17 (1) The Committee shall receive necessary and  
18 appropriate administrative support from the Depart-  
19 ment of Health and Human Services.

20 (2) Members of the Committee shall be ap-  
21 pointed for a term of three years, and may serve for  
22 an unlimited number of terms if reappointed.

23 (3) The Committee shall meet no less than two  
24 times per year.

1           (4) Members of the Committee shall not receive  
2       additional compensation for their service. Such  
3       members may receive reimbursement for appropriate  
4       and additional expenses that are incurred through  
5       service on the Committee which would not have in-  
6       curred had they not been a member of the Com-  
7       mittee.

8   **SEC. 215. REPORT TO CONGRESS.**

9       The Secretary shall prepare and submit to the Con-  
10   gress, after consultation and comment by the Advisory  
11   Committee, an annual report regarding the prevalence and  
12   incidence of autism and other pervasive developmental dis-  
13   orders, the results of research into the etiology of autism  
14   and other pervasive developmental disorders, public health  
15   responses to known or preventable causes of autism and  
16   other pervasive developmental disorders, and the need for  
17   additional research into promising lines of scientific in-  
18   quiry.

19   **SEC. 216. DEFINITION.**

20       For purposes of this chapter, the term “State” means  
21   each of the several States, the District of Columbia, the  
22   Commonwealth of Puerto Rico, American Samoa, Guam,  
23   the Commonwealth of the Northern Mariana Islands, the  
24   Virgin Islands, and the Trust Territory of the Pacific Is-  
25   lands.

1 **SEC. 217. AUTHORIZATION OF APPROPRIATIONS.**

2 For the purpose of carrying out this chapter, there  
3 are authorized to be appropriated such sums as may be  
4 necessary for each of the fiscal years 2000 through 2003.

5 **CHAPTER 2—EXPANSION, INTENSIFICA-**  
6 **TION, AND COORDINATION OF ACTIVI-**  
7 **TIES OF DEPARTMENT OF HEALTH**  
8 **AND HUMAN SERVICES WITH RESPECT**  
9 **TO AUTISM**

10 **SEC. 218. SHORT TITLE.**

11 This Act may be cited as the “Advancement in Pedi-  
12 atric Autism Research Act of 1999”.

13 **SEC. 218A. EXPANSION, INTENSIFICATION, AND COORDINA-**  
14 **TION OF ACTIVITIES OF NATIONAL INSTI-**  
15 **TUTES OF HEALTH.**

16 Part B of title IV of the Public Health Service Act  
17 (42 U.S.C. 284 et seq.) is amended by adding at the end  
18 the following section:

19 “AUTISM

20 “SEC. 409C. (a) IN GENERAL.—

21 “(1) EXPANSION OF ACTIVITIES.—The Director  
22 of NIH (in this section referred to as the ‘Director’)  
23 shall expand, intensify, and coordinate the activities  
24 of the National Institutes of Health with respect to  
25 research on autism.

1           “(2) ADMINISTRATION OF PROGRAM; COLLABO-  
2           RATION AMONG AGENCIES.—The Director shall carry  
3           out this section acting through the Director of the  
4           National Institute of Mental Health and in collabo-  
5           ration with any other agencies that the Director de-  
6           termines appropriate.

7           “(b) CENTERS OF EXCELLENCE.—

8           “(1) IN GENERAL.—The Director shall under  
9           subsection (a)(1) make awards of grants and con-  
10          tracts to public or nonprofit private entities to pay  
11          all or part of the cost of planning, establishing, im-  
12          proving, and providing basic operating support for  
13          centers of excellence regarding research on autism.

14          “(2) RESEARCH.—Each center under para-  
15          graph (1) shall conduct basic and clinical research  
16          into autism. Such research should include investiga-  
17          tions into the cause, diagnosis, early detection, pre-  
18          vention, control, and treatment of autism. These  
19          centers, as a group, shall conduct research including  
20          but not limited to the fields of developmental  
21          neurobiology, genetics, and psychopharmacology.

22          “(3) SERVICES FOR PATIENTS.—A center under  
23          paragraph (1) may expend amounts provided under  
24          such paragraph to carry out a program to make in-  
25          dividuals aware of opportunities to participate as

1 subjects in research conducted by the centers. The  
2 program may, in accordance with such criteria as  
3 the Director may establish, provide to such subjects  
4 referrals for health and other services, and such pa-  
5 tient care costs as are required for research. The ex-  
6 tent to which the center can demonstrate availability  
7 and access to clinical services shall be considered by  
8 the Director in decisions about awarding the grants  
9 to applicants which meet the scientific criteria for  
10 funding.

11 “(4) COORDINATION OF CENTERS; REPORTS.—  
12 The Director shall, as appropriate, provide for the  
13 coordination of information among centers under  
14 paragraph (1) and ensure regular communication  
15 between such centers, and may require the periodic  
16 preparation of reports on the activities of the centers  
17 and the submission of the reports to the Director.

18 “(5) ORGANIZATION OF CENTERS.—Each cen-  
19 ter under paragraph (1) shall use the facilities of a  
20 single institution, or be formed from a consortium of  
21 cooperating institutions, meeting such requirements  
22 as may be prescribed by the Director.

23 “(6) NUMBER OF CENTERS; DURATION OF SUP-  
24 PORT.—The Director shall provide for the establish-  
25 ment of not less than five centers under paragraph

1       (1). Support of such a center may be for a period  
2       not exceeding 5 years. Such period may be extended  
3       for one or more additional periods not exceeding 5  
4       years if the operations of such center have been re-  
5       viewed by an appropriate technical and scientific  
6       peer review group established by the Director and if  
7       such group has recommended to the Director that  
8       such period should be extended.

9       “(c) FACILITATION OF RESEARCH.—The Director  
10      shall under subsection (a)(1) provide for a program under  
11      which samples of tissues and genetic materials that are  
12      of use in research on autism are donated, collected, pre-  
13      served, and made available for such research. The pro-  
14      gram shall be carried out in accordance with accepted sci-  
15      entific and medical standards for the donation, collection,  
16      and preservation of such samples.

17      “(d) PUBLIC INPUT.—The Director shall under sub-  
18      section (a)(1) provide for means through which the public  
19      can obtain information on the existing and planned pro-  
20      grams and activities of the National Institutes of Health  
21      with respect to autism and through which the Director can  
22      receive comments from the public regarding such pro-  
23      grams and activities.

24      “(e) FUNDING.—For the purpose of carrying out this  
25      section, there are authorized to be appropriated such sums

1 as may be necessary for each of the fiscal years 2000  
 2 through 2003. Such authorizations of appropriations are  
 3 in addition to any other authorization of appropriations  
 4 that is available for such purpose.”.

5 **SEC. 219. DEVELOPMENTAL DISABILITIES SURVEILLANCE**  
 6 **AND RESEARCH PROGRAMS.**

7 (a) NATIONAL AUTISM AND PERVASIVE DEVELOP-  
 8 MENTAL DISABILITIES SURVEILLANCE PROGRAM.—The  
 9 Secretary of Health and Human Services (in this chapter  
 10 referred to as the “Secretary”), acting through the Direc-  
 11 tor of the Centers for Disease Control and Prevention,  
 12 may make awards of grants and cooperative agreements  
 13 for the collection, analysis, and reporting of data on au-  
 14 tism and pervasive developmental disabilities. An entity  
 15 may receive such an award only if the entity is a public  
 16 or nonprofit private entity (including health departments  
 17 of States and political subdivisions of States, and includ-  
 18 ing universities and other educational entities). In making  
 19 such awards, the Secretary may provide direct technical  
 20 assistance in lieu of cash.

21 (b) CENTERS OF EXCELLENCE IN AUTISM AND PER-  
 22 VASIVE DEVELOPMENTAL DISABILITIES EPIDEMI-  
 23 OLOGY.—

24 (1) IN GENERAL.—The Secretary, acting  
 25 through the Director of the Centers for Disease

1 Control and Prevention, shall establish not less than  
2 3, regional centers of excellence in autism and perva-  
3 sive developmental disabilities epidemiology for the  
4 purpose of collecting and analyzing information on  
5 the number, incidence, correlates, and causes of au-  
6 tism and related developmental disabilities.

7 (2) RECIPIENTS OF AWARDS FOR ESTABLISH-  
8 MENT OF CENTERS.—Centers under paragraph (1)  
9 shall be established and operated through the award-  
10 ing of grants or cooperative agreements to public or  
11 nonprofit private entities that conduct research, in-  
12 cluding health departments of States and political  
13 subdivisions of States, and including universities and  
14 other educational entities.

15 (3) CERTAIN REQUIREMENTS.—An award for a  
16 center under paragraph (1) may be made only if the  
17 entity involved submits to the Secretary an applica-  
18 tion containing such agreements and information as  
19 the Secretary may require, including an agreement  
20 that the center involved will operate in accordance  
21 with the following:

22 (A) The center will collect, analyze, and re-  
23 port autism and pervasive developmental dis-  
24 abilities data according to guidelines prescribed  
25 by the Director, after consultation with relevant



1 State and local public health officials, private  
2 sector developmental disability researchers, and  
3 advocates for those with developmental disabili-  
4 ties.

5 (B) The center will assist with the develop-  
6 ment and coordination of State autism and per-  
7 vasive developmental disabilities surveillance ef-  
8 forts within a region.

9 (C) The center will identify eligible cases  
10 and controls through its surveillance systems  
11 and conduct research into factors which may  
12 cause autism and related developmental disabili-  
13 ties. Each program will develop or extend an  
14 area of special research expertise (including ge-  
15 netics, environmental exposure to contaminants,  
16 immunology, and other relevant research spe-  
17 cialty areas).

18 (c) CLEARINGHOUSE.—The Secretary, acting  
19 through the Director of the Centers for Disease Control  
20 and Prevention, shall carry out the following:

21 (1) The Secretary shall establish a clearing-  
22 house within the Centers for Disease Control and  
23 Prevention for the collection and storage of data  
24 generated from the monitoring programs created by  
25 this chapter. Through the clearinghouse, such Cen-

1       ters shall serve as the coordinating agency for au-  
2       tism and pervasive developmental disabilities surveil-  
3       lance activities. The functions of such a clearing-  
4       house shall include facilitating the coordination of  
5       research and policy development relating to the epi-  
6       demiology of autism and other pervasive develop-  
7       mental disabilities.

8           (2) The Secretary, acting through the Centers  
9       for Disease Control and Prevention, shall coordinate  
10      the Federal response to requests for assistance from  
11      State health department officials regarding potential  
12      or alleged autism or developmental disability clus-  
13      ters.

14      (d) DEFINITION.—In this chapter, the term “State”  
15      means each of the several States, the District of Columbia,  
16      the Commonwealth of Puerto Rico, American Samoa,  
17      Guam, the Commonwealth of the Northern Mariana Is-  
18      lands, the Virgin Islands, and the Trust Territory of the  
19      Pacific Islands.

20      (e) AUTHORIZATION OF APPROPRIATIONS.—For the  
21      purpose of carrying out this section, there are authorized  
22      to be appropriated such sums as may be necessary for  
23      each of the fiscal years 2000 through 2003.

1 **SEC. 220. INFORMATION AND EDUCATION.**

2 (a) IN GENERAL.—The Secretary shall establish and  
3 implement a program to provide information and edu-  
4 cation on autism to health professionals and the general  
5 public, including information and education on advances  
6 in the diagnosis and treatment of autism and training and  
7 continuing education through programs for scientists, phy-  
8 sicians, and other health professionals who provide care  
9 for patients with autism.

10 (b) STIPENDS.—The Secretary may use amounts  
11 made available under this section to provide stipends for  
12 health professionals who are enrolled in training programs  
13 under this section.

14 (c) AUTHORIZATION OF APPROPRIATIONS.—For the  
15 purpose of carrying out this section, there are authorized  
16 to be appropriated such sums as may be necessary for  
17 each of the fiscal years 2000 through 2003.

18 **SEC. 220A. INTERAGENCY AUTISM COORDINATING COM-**  
19 **MITTEE.**

20 (a) ESTABLISHMENT.—The Secretary shall establish  
21 a committee to be known as the “Autism Coordinating  
22 Committee” (in this section referred to as the “Com-  
23 mittee”) to coordinate all efforts within the Department  
24 of Health and Human Services concerning autism, includ-  
25 ing activities carried out through the National Institutes  
26 of Health and the Centers for Disease Control and Pre-

1 vention under this chapter (and the amendment made by  
2 this chapter).

3 (b) MEMBERSHIP.—

4 (1) IN GENERAL.—The Committee shall be  
5 composed of the Directors of such national research  
6 institutes, of the Centers for Disease Control and  
7 Prevention, and of such other agencies and such  
8 other officials as the Secretary determines appro-  
9 priate.

10 (2) ADDITIONAL MEMBERS.—If determined ap-  
11 propriate by the Secretary, the Secretary may ap-  
12 point to the Committee—

13 (A) parents or legal guardians of individ-  
14 uals with autism or other pervasive develop-  
15 mental disorders; and

16 (B) representatives of other governmental  
17 agencies that serve children with autism such  
18 as the Department of Education.

19 (c) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;  
20 OTHER PROVISIONS.—The following shall apply with re-  
21 spect to the Committee:

22 (1) The Committee shall receive necessary and  
23 appropriate administrative support from the Depart-  
24 ment of Health and Human Services.

1           (2) Members of the Committee appointed under  
 2           subsection (b)(2)(A) shall serve for a term of 3  
 3           years, and may serve for an unlimited number of  
 4           terms if reappointed.

5           (3) The Committee shall meet not less than 2  
 6           times per year.

7 **SEC. 220B. REPORT TO CONGRESS.**

8           Not later than January 1, 2000, and each January  
 9           1 thereafter, the Secretary shall prepare and submit to  
 10          the appropriate committees of Congress, a report con-  
 11          cerning the implementation of this chapter and the  
 12          amendments made by this chapter.

13 **Subtitle C—Poison Control Center**  
 14 **Enhancement and Awareness**

15 **SEC. 221. SHORT TITLE.**

16          This subtitle may be cited as the “Poison Control  
 17          Center Enhancement and Awareness Act”.

18 **SEC. 222. DEFINITION.**

19          For purposes of this subtitle, the term “Secretary”  
 20          means the Secretary of Health and Human Services.

21 **SEC. 223. ESTABLISHMENT OF A NATIONAL TOLL-FREE**  
 22 **NUMBER.**

23          (a) IN GENERAL.—The Secretary shall provide co-  
 24          ordination and assistance to regional poison control cen-

1 ters for the establishment of a nationwide toll-free phone  
2 number to be used to access such centers.

3 (b) RULE OF CONSTRUCTION.—Nothing in this sec-  
4 tion shall be construed as prohibiting the establishment  
5 or continued operation of any privately funded nationwide  
6 toll-free phone number used to provide advice and other  
7 assistance for poisonings or accidental exposures.

8 (c) AUTHORIZATION OF APPROPRIATIONS.—For the  
9 purpose of carrying out this section, there are authorized  
10 to be appropriated such sums as may be necessary for  
11 each of the fiscal years 2000 through 2003. Funds appro-  
12 priated under this subsection shall not be used to fund  
13 any toll-free phone number described in subsection (b).

14 **SEC. 224. ESTABLISHMENT OF NATIONWIDE MEDIA**  
15 **CAMPAIGN.**

16 (a) IN GENERAL.—The Secretary shall establish a  
17 national media campaign to educate the public and health  
18 care providers about poison prevention and the availability  
19 of poison control resources in local communities and to  
20 conduct advertising campaigns concerning the nationwide  
21 toll-free number established under section 223.

22 (b) CONTRACT WITH ENTITY.—The Secretary may  
23 carry out subsection (a) by entering into contracts with  
24 1 or more nationally recognized media firms for the devel-

1 opment and distribution of monthly television, radio, and  
2 newspaper public service announcements.

3 (c) AUTHORIZATION OF APPROPRIATIONS.—For the  
4 purpose of carrying out this section, there are authorized  
5 to be appropriated such sums as may be necessary for  
6 each of the fiscal years 2000 through 2003.

7 **SEC. 225. ESTABLISHMENT OF A GRANT PROGRAM.**

8 (a) REGIONAL POISON CONTROL CENTERS.—The  
9 Secretary shall award grants to certified regional poison  
10 control centers for the purposes of achieving the financial  
11 stability of such centers, and for preventing and providing  
12 treatment recommendations for poisonings.

13 (b) OTHER IMPROVEMENTS.—The Secretary shall  
14 also use amounts received under this section to—

- 15 (1) develop standard education programs;
- 16 (2) develop standard patient management pro-  
17 tocols for commonly encountered toxic exposures;
- 18 (3) improve and expand the poison control data  
19 collection systems;
- 20 (4) improve national toxic exposure surveillance;
- 21 and
- 22 (5) expand the physician/medical toxicologist  
23 supervision of poison control centers.

1       (c) CERTIFICATION.—Except as provided in sub-  
2 section (d), the Secretary may make a grant to a center  
3 under subsection (a) only if—

4           (1) the center has been certified by a profes-  
5 sional organization in the field of poison control, and  
6 the Secretary has approved the organization as hav-  
7 ing in effect standards for certification that reason-  
8 ably provide for the protection of the public health  
9 with respect to poisoning; or

10          (2) the center has been certified by a State gov-  
11 ernment, and the Secretary has approved the State  
12 government as having in effect standards for certifi-  
13 cation that reasonably provide for the protection of  
14 the public health with respect to poisoning.

15       (d) WAIVER OF CERTIFICATION REQUIREMENTS.—

16           (1) IN GENERAL.—The Secretary may grant a  
17 waiver of the certification requirement of subsection  
18 (c) with respect to a noncertified poison control cen-  
19 ter or a newly established center that applies for a  
20 grant under this section if such center can reason-  
21 ably demonstrate that the center will obtain such a  
22 certification within a reasonable period of time as  
23 determined appropriate by the Secretary.



1           (2) RENEWAL.—The Secretary may only renew  
2       a waiver under paragraph (1) for a period of 3  
3       years.

4       (e) SUPPLEMENT NOT SUPPLANT.—Amounts made  
5       available to a poison control center under this section shall  
6       be used to supplement and not supplant other Federal,  
7       State, or local funds provided for such center.

8       (f) MAINTENANCE OF EFFORT.—A poison control  
9       center, in utilizing the proceeds of a grant under this sec-  
10      tion, shall maintain the expenditures of the center for ac-  
11      tivities of the center at a level that is not less than the  
12      level of such expenditures maintained by the center for  
13      the fiscal year preceding the fiscal year for which the  
14      grant is received.

15      (g) MATCHING REQUIREMENT.—The Secretary may  
16      impose a matching requirement with respect to amounts  
17      provided under a grant under this section if the Secretary  
18      determines appropriate.

19      (h) AUTHORIZATION OF APPROPRIATIONS.—For the  
20      purpose of carrying out this section, there are authorized  
21      to be appropriated such sums as may be necessary for  
22      each of the fiscal years 2000 through 2003.

**Subtitle D—Birth Defects**  
**Prevention Activities**  
**CHAPTER 1—FOLIC ACID**

**SEC. 231. SHORT TITLE.**

This chapter may be cited as the “Folic Acid Promotion and Birth Defects Prevention Act of 1999”.

**SEC. 232. PROGRAM REGARDING EFFECTS OF FOLIC ACID**  
**IN PREVENTION OF BIRTH DEFECTS.**

Part B of title III of the Public Health Service Act (42 U.S.C. 243 et seq.) is amended by inserting after section 317G the following section:

“EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH  
DEFECTS

“SEC. 317H. (a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out a program (directly or through grants or contracts) for the following purposes:

“(1) To provide education and training for health professionals and the general public for purposes of explaining the effects of folic acid in preventing birth defects and for purposes of encouraging each woman of reproductive capacity (whether or not planning a pregnancy) to consume on a daily basis a dietary supplement that provides an appropriate level of folic acid.

1           “(2) To conduct research with respect to such  
2           education and training, including identifying effective  
3           strategies for increasing the rate of consumption  
4           of folic acid by women of reproductive capacity.

5           “(3) To conduct research to increase the understanding  
6           of the effects of folic acid in preventing  
7           birth defects, including understanding with respect  
8           to cleft lip, cleft palate, and heart defects.

9           “(4) To provide for appropriate epidemiological  
10          activities regarding folic acid and birth defects, including  
11          epidemiological activities regarding neural  
12          tube defects.

13          “(b) CONSULTATIONS WITH STATES AND PRIVATE  
14          ENTITIES.—In carrying out subsection (a), the Secretary  
15          shall consult with the States and with other appropriate  
16          public or private entities, including national nonprofit private  
17          organizations, health professionals, and providers of  
18          health insurance and health plans.

19          “(c) TECHNICAL ASSISTANCE.—The Secretary may  
20          (directly or through grants or contracts) provide technical  
21          assistance to public and nonprofit private entities in carrying  
22          out the activities described in subsection (a).

23          “(d) EVALUATIONS.—The Secretary shall (directly or  
24          through grants or contracts) provide for the evaluation of  
25          activities under subsection (a) in order to determine the

1 extent to which such activities have been effective in car-  
 2 rying out the purposes of the program under such sub-  
 3 section, including the effects on various demographic pop-  
 4 ulations. Methods of evaluation under the preceding sen-  
 5 tence may include surveys of knowledge and attitudes on  
 6 the consumption of folic acid and on blood folate levels.  
 7 Such methods may include complete and timely moni-  
 8 toring of infants who are born with neural tube defects.  
 9 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the  
 10 purpose of carrying out this section, there are authorized  
 11 to be appropriated such sums as may be necessary for  
 12 each of the fiscal years 2000 through 2003.”.

13 **CHAPTER 2—NATIONAL CENTER ON**  
 14 **BIRTH DEFECTS AND DEVELOP-**  
 15 **MENTAL DISABILITIES**

16 **SEC. 236. NATIONAL CENTER ON BIRTH DEFECTS AND**  
 17 **DEVELOPMENTAL DISABILITIES.**

18 Title III of the Public Health Service Act (42 U.S.C.  
 19 241 et seq.) is amended—

20 (1) in part O—

21 (A) by redesignating sections 399G  
 22 through 399J as sections 399M through 399P,  
 23 respectively;

1 (B) in section 399O(b) (as so redesign-  
 2 nated), by striking “section 399G(d)” and in-  
 3 serting “section 399M(d)”; and

4 (C) in section 399P (as so redesignated),  
 5 by striking “section 399G(d)(1)” and inserting  
 6 “section 399M(d)(1)”; and

7 (2) by adding at the end the following part:

8 “PART P—PEDIATRIC PUBLIC HEALTH PROMOTION

9 **“SEC. 399Q. NATIONAL CENTER ON BIRTH DEFECTS AND**  
 10 **DEVELOPMENTAL DISABILITIES.**

11 “(a) ESTABLISHMENT.—There is established within  
 12 the Centers for Disease Control and Prevention a center  
 13 to be known as the National Center on Birth Defects and  
 14 Developmental Disabilities.

15 “(b) PURPOSE.—The general purpose of the National  
 16 Center established under subsection (a) shall be to—

17 “(1) collect, analyze, and make available data  
 18 on birth defects, including data on the causes of  
 19 such defects and on the incidence and prevalence of  
 20 such defects;

21 “(2) conduct applied epidemiological research  
 22 on the prevention of such defects; and

23 “(3) provide information and education to the  
 24 public on the prevention of such defects.

1       “(c) DIRECTOR.—The National Center established  
2 under subsection (a) shall be headed by a director to be  
3 appointed by the Secretary.

4       “(d) TRANSFERS.—There shall be transferred to the  
5 National Center established under subsection (a) all activi-  
6 ties, budgets and personnel of the National Center for En-  
7 vironmental Health that relate to birth defects, folic acid,  
8 cerebral palsy, mental retardation, child development,  
9 newborn screening, autism, fragile X syndrome, fetal alco-  
10 hol syndrome, pediatric genetics, and disability prevention.

11       “(e) AUTHORIZATION OF APPROPRIATIONS.—For the  
12 purpose of carrying out this section, there are authorized  
13 to be appropriated such sums as may be necessary for  
14 each of the fiscal years 2000 through 2003.”.

15       **Subtitle E—Safe Motherhood Moni-**  
16       **toring and Prevention Research**

17       **SEC. 241. SHORT TITLE.**

18       This subtitle may be cited as the “Safe Motherhood  
19 Monitoring and Prevention Research Act”.

20       **SEC. 242. AMENDMENT TO PUBLIC HEALTH SERVICE ACT.**

21       Title III of the Public Health Service Act, as amend-  
22 ed by section 236 of this Act, is amended by adding at  
23 the end the following part:

1 “PART Q—SAFE MOTHERHOOD

2 “SEC. 399R. SAFE MOTHERHOOD MONITORING.

3 “(a) PURPOSE.—It is the purpose of this section to  
4 develop monitoring systems at the local, State, and na-  
5 tional level to better understand the burden of maternal  
6 complications and mortality and to decrease the disparities  
7 among population at risk of death and complications from  
8 pregnancy.

9 “(b) ACTIVITIES.—For the purpose described in sub-  
10 section (a), the Secretary may carry out the following ac-  
11 tivities:

12 “(1) The Secretary may establish and imple-  
13 ment a national monitoring and surveillance pro-  
14 gram to identify and promote the investigation of  
15 deaths and severe complications that occur during  
16 pregnancy.

17 “(2) The Secretary may expand the Pregnancy  
18 Risk Assessment Monitoring System to provide sur-  
19 veillance and collect data in each of the 50 States.

20 “(3) The Secretary may expand the Maternal  
21 and Child Health Epidemiology Program to provide  
22 technical support, financial assistance, or the time-  
23 limited assignment of senior epidemiologists to ma-  
24 ternal and child health programs in each of the 50  
25 States.

1 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
2 purpose of carrying out this section, there are authorized  
3 to be appropriated such sums as may be necessary for  
4 each of the fiscal years 2000 through 2003.”.

5 **“SEC. 399S. PREVENTION RESEARCH TO ENSURE SAFE**  
6 **MOTHERHOOD.**

7 “(a) PURPOSE.—It is the purpose of this section to  
8 provide the Secretary with the authority to further expand  
9 research concerning risk factors, prevention strategies,  
10 and the roles of the family, health care providers and the  
11 community in safe motherhood.

12 “(b) RESEARCH.—The Secretary may carry out ac-  
13 tivities to expand research relating to—

14 “(1) encouraging preconception counseling, es-  
15 pecially for at risk populations such as diabetics;

16 “(2) the identification of critical components of  
17 prenatal delivery and postpartum care;

18 “(3) the identification of outreach and support  
19 services, such as folic acid education, that are avail-  
20 able for pregnant women;

21 “(4) the identification of women who are at  
22 high risk for complications;

23 “(5) preventing preterm delivery;

24 “(6) preventing urinary tract infections;

25 “(7) preventing unnecessary caesarean sections;



6 “(10) preventing smoking, alcohol and illegal  
7 drug usage before, during and after pregnancy;

10                   “(12) other areas determined appropriate by  
11           the Secretary.

16 “SEC. 399T. PREVENTION PROGRAMS TO ENSURE SAFE  
17 MOTHERHOOD.

20 “(1) public education campaigns on healthy  
21 pregnancies and the building of partnerships with  
22 outside organizations concerned about safe mother-  
23 hood;

24 “(2) education programs for physicians, nurses  
25 and other health care providers; and

1           “(3) activities to promote community support  
2           services for pregnant women.

3           “(b) AUTHORIZATION OF APPROPRIATIONS.—For the  
4           purpose of carrying out this section, there are authorized  
5           to be appropriated such sums as may be necessary for  
6           each of the fiscal years 2000 through 2003.”.

## 7       **Subtitle F—Pregnant Mothers and** 8       **Infants Health Promotion**

### 9       **SEC. 251. SHORT TITLE.**

10           This subtitle may be cited as the “Pregnant Mothers  
11           and Infants Health Protection Act”.

### 12       **SEC. 252. ESTABLISHMENT.**

13           Title III of the Public Health Service Act, as amend-  
14           ed by section 242 of this Act, is amended by adding at  
15           the end the following part:

16                       “PART R—ADDITIONAL PROGRAMS  
17       **“SEC. 399U. PROGRAMS REGARDING PRENATAL AND POST-**  
18                       **NATAL HEALTH.**

19           “(a) IN GENERAL.—The Secretary shall carry out  
20           programs—

21                       “(1) to collect, analyze, and make available data  
22                       on prenatal smoking, alcohol and illegal drug usage,  
23                       including data on the implications of such activities  
24                       and on the incidence and prevalence of such activi-  
25                       ties and their implications;

1           “(2) to conduct applied epidemiological research  
2           on the prevention of prenatal and postnatal smoking,  
3           alcohol and illegal drug usage;

4           “(3) to support, conduct, and evaluate the ef-  
5           fectiveness of educational and cessation programs;  
6           and

7           “(4) to provide information and education to  
8           the public on the prevention and implications of pre-  
9           natal and postnatal smoking, alcohol and illegal drug  
10          usage.

11          “(b) GRANTS.—In carrying out subsection (a), the  
12          Secretary may award grants to and enter into contracts  
13          with States, local governments, scientific and academic in-  
14          stitutions, Federally qualified health centers, and other  
15          public and nonprofit entities, and may provide technical  
16          and consultative assistance to such entities.

17          “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
18          purpose of carrying out this section, there are authorized  
19          to be appropriated such sums as may be necessary for  
20          each of the fiscal years 2000 through 2003.”.

## **Subtitle G—Utilization of Preventive Health Services**

### **SEC. 261. GRANTS REGARDING UTILIZATION OF PREVENTIVE HEALTH SERVICES.**

Part D of title III of the Public Health Service Act (42 U.S.C. 254b et seq.) is amended by adding at the end the following section:

#### **“SEC. 330D. CENTERS FOR STRATEGIES ON FACILITATING UTILIZATION OF PREVENTIVE HEALTH SERVICES AMONG VARIOUS POPULATIONS.**

“(a) IN GENERAL.—The Secretary, acting through the appropriate agencies of the Public Health Service, shall make grants to public or nonprofit private entities for the establishment and operation of regional centers whose purpose is to identify particular populations of patients and facilitate the appropriate utilization of preventive health services by patients in the populations through developing and disseminating strategies to improve the methods used by public and private health care programs and providers in interacting with such patients.

“(b) RESEARCH AND TRAINING.—The activities carried out by a center under subsection (a) may include establishing programs of research and training with respect to the purpose described in such subsection, including the

1 development of curricula for training individuals in imple-  
2 menting the strategies developed under such subsection.

3       “(c) QUALITY MANAGEMENT.—A condition for the  
4 receipt of a grant under subsection (a) is that the appli-  
5 cant involved agree that, in order to ensure that the strat-  
6 egies developed under such subsection take into account  
7 principles of quality management with respect to con-  
8 sumer satisfaction, the applicant will make arrangements  
9 with one or more private entities that have experience in  
10 applying such principles.

11       “(d) PRIORITY REGARDING INFANTS AND CHIL-  
12 DREN.—In carrying out the purpose described in sub-  
13 section (a), the Secretary shall give priority to various  
14 populations of infants, young children, and their mothers.

15       “(e) EVALUATIONS.—The Secretary, acting through  
16 the appropriate agencies of the Public Health Service,  
17 shall (directly or through grants or contracts) provide for  
18 the evaluation of strategies under subsection (a) in order  
19 to determine the extent to which the strategies have been  
20 effective in facilitating the appropriate utilization of pre-  
21 ventive health services in the populations with respect to  
22 which the strategies were developed.

23       “(f) AUTHORIZATION OF APPROPRIATIONS.—For the  
24 purpose of carrying out this section, there are authorized

1 to be appropriated such sums as may be necessary for  
 2 each of the fiscal years 2000 through 2003.”.

## 3                   **Subtitle H—Research and** 4                   **Development Regarding Fragile X**

### 5   **SEC. 266. SHORT TITLE.**

6           This subtitle may be cited as the “Fragile X Research  
 7 Breakthrough Act of 1999”.

### 8   **SEC. 267. NATIONAL INSTITUTE OF CHILD HEALTH AND** 9                   **HUMAN DEVELOPMENT; RESEARCH ON FRAG-** 10                  **ILE X.**

11          Subpart 7 of part C of title IV of the Public Health  
 12 Service Act, as amended by section 103 of this Act, is  
 13 amended by adding at the end the following section:

14                                   “FRAGILE X

15          “SEC. 452F. (a) EXPANSION AND COORDINATION OF  
 16 RESEARCH ACTIVITIES.—The Director of the Institute,  
 17 after consultation with the advisory council for the Insti-  
 18 tute, shall expand, intensify, and coordinate the activities  
 19 of the Institute with respect to research on the disease  
 20 known as fragile X.

21          “(b) RESEARCH CENTERS.—

22               “(1) IN GENERAL.—The Director of the Insti-  
 23 tute, after consultation with the advisory council for  
 24 the Institute, shall make grants to, or enter into  
 25 contracts with, public or nonprofit private entities  
 26 for the development and operation of centers to con-

1 duct research for the purposes of improving the di-  
2 agnosis and treatment of, and finding the cure for,  
3 fragile X.

4 “(2) NUMBER OF CENTERS.—In carrying out  
5 paragraph (1), the Director of the Institute shall, to  
6 the extent that amounts are appropriated, provide  
7 for the establishment of at least three fragile X re-  
8 search centers.

9 “(3) ACTIVITIES.—

10 “(A) IN GENERAL.—Each center assisted  
11 under paragraph (1) shall, with respect to frag-  
12 ile X—

13 “(i) conduct basic and clinical re-  
14 search, which may include clinical trials  
15 of—

16 “(I) new or improved diagnostic  
17 methods; and

18 “(II) drugs or other treatment  
19 approaches; and

20 “(ii) conduct research to find a cure.

21 “(B) FEES.—A center may use funds pro-  
22 vided under paragraph (1) to provide fees to in-  
23 dividuals serving as subjects in clinical trials  
24 conducted under subparagraph (A).

1           “(4) COORDINATION AMONG CENTERS.—The  
2       Director of the Institute shall, as appropriate, pro-  
3       vide for the coordination of the activities of the cen-  
4       ters assisted under this section, including providing  
5       for the exchange of information among the centers.

6           “(5) CERTAIN ADMINISTRATIVE REQUIRE-  
7       MENTS.—Each center assisted under paragraph (1)  
8       shall use the facilities of a single institution, or be  
9       formed from a consortium of cooperating institu-  
10      tions, meeting such requirements as may be pre-  
11      scribed by the Director of the Institute.

12          “(6) DURATION OF SUPPORT.—Support may be  
13      provided to a center under paragraph (1) for a pe-  
14      riod not exceeding 5 years. Such period may be ex-  
15      tended for one or more additional periods, each of  
16      which may not exceed 5 years, if the operations of  
17      such center have been reviewed by an appropriate  
18      technical and scientific peer review group established  
19      by the Director and if such group has recommended  
20      to the Director that such period be extended.

21          “(7) AUTHORIZATION OF APPROPRIATIONS.—  
22      For the purpose of carrying out this subsection,  
23      there are authorized to be appropriated such sums  
24      as may be necessary for each of the fiscal years  
25      2000 through 2003.”.



1 **SEC. 268. NATIONAL INSTITUTE OF CHILD HEALTH AND**  
2 **HUMAN DEVELOPMENT; LOAN REPAYMENT**  
3 **PROGRAM REGARDING RESEARCH ON FRAG-**  
4 **ILE X.**

5 Part G of title IV of the Public Health Service Act  
6 (42 U.S.C. 288 et seq.) is amended by inserting after sec-  
7 tion 487E the following section:

8 “LOAN REPAYMENT PROGRAM REGARDING RESEARCH ON  
9 FRAGILE X

10 “SEC. 487F. (a) IN GENERAL.—The Secretary, in  
11 consultation with the Director of the National Institute  
12 of Child Health and Human Development, shall establish  
13 a program under which the Federal Government enters  
14 into contracts with qualified health professionals (includ-  
15 ing graduate students) who agree to conduct research re-  
16 garding fragile X in consideration of the Federal Govern-  
17 ment’s agreement to repay, for each year of such service,  
18 not more than \$35,000 of the principal and interest of  
19 the educational loans owed by such health professionals.

20 “(b) APPLICABILITY OF CERTAIN PROVISIONS.—  
21 With respect to the National Health Service Corps Loan  
22 Repayment Program established in subpart III of part D  
23 of title III, the provisions of such subpart (including sec-  
24 tion 338B(g)(3)) shall, except as inconsistent with sub-  
25 section (a) of this section, apply to the program estab-  
26 lished in such subsection in the same manner and to the

1 same extent as such provisions apply to the National  
 2 Health Service Corps Loan Repayment Program estab-  
 3 lished in such subpart.

4 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
 5 purpose of carrying out this section, there are authorized  
 6 to be appropriated such sums as may be necessary for  
 7 each of the fiscal years 2000 through 2003.”.

## 8 **Subtitle I—Children and Epilepsy**

### 9 **SEC. 271. PROGRAMS OF THE CENTERS FOR DISEASE CON-** 10 **TROL AND PREVENTION; NATIONAL PUBLIC** 11 **HEALTH CAMPAIGN ON EPILEPSY.**

12 (a) IN GENERAL.—The Secretary of Health and  
 13 Human Services (in this subtitle referred to as the “Sec-  
 14 retary”), acting through the Director of the Centers for  
 15 Disease Control and Prevention, shall develop and imple-  
 16 ment public health surveillance, education, research, and  
 17 intervention strategies to improve the lives of persons with  
 18 epilepsy, with a particular emphasis on children. Such  
 19 projects may be carried out by the Secretary directly and  
 20 through awards of grants or contracts to public or non-  
 21 profit private entities. The Secretary may directly or  
 22 through such awards provide technical assistance with re-  
 23 spect to the planning, development, and operation of such  
 24 projects.

1       (b) CERTAIN ACTIVITIES.—Activities under sub-  
2 section (a) shall include—

3           (1) expanding current surveillance activities  
4       through existing monitoring systems and improving  
5       registries that maintain data on individuals with epi-  
6       lepsy, including children;

7           (2) enhancing research activities on the man-  
8       agement and control of epilepsy;

9           (3) implementing public and professional infor-  
10       mation and education programs regarding epilepsy,  
11       including initiatives which promote effective manage-  
12       ment and control of the disease through children's  
13       programs which are targeted to parents, schools,  
14       daycare providers, patients;

15          (4) undertaking educational efforts with the  
16       media, providers of health care, schools and others  
17       regarding stigmas and secondary disabilities related  
18       to epilepsy and seizures, and also its affects on  
19       youth;

20          (5) utilizing and expanding partnerships with  
21       organizations with experience addressing the health  
22       and related needs of people with disabilities; and

23          (6) other activities the Secretary deems appro-  
24       prium.

1       (c) COORDINATION OF ACTIVITIES.—The Secretary  
 2 shall ensure that activities under this section are coordi-  
 3 nated as appropriate with other agencies of the Public  
 4 Health Service that carry out activities regarding epilepsy  
 5 and seizure.

6       (d) AUTHORIZATION OF APPROPRIATIONS.—For the  
 7 purpose of carrying out this section, there are authorized  
 8 to be appropriated such sums as may be necessary for  
 9 each of the fiscal years 2000 through 2003.

10 **SEC. 272. PROGRAMS OF HEALTH RESOURCES AND SERV-**  
 11 **ICES ADMINISTRATION; STATE AND LOCAL**  
 12 **GRANTS FOR SEIZURE DISORDER DEM-**  
 13 **ONSTRATION PROJECTS IN MEDICALLY UN-**  
 14 **DERSERVED AREAS.**

15       (a) IN GENERAL.—The Secretary, acting through the  
 16 Administrator of the Health Resources and Services Ad-  
 17 ministration, may make grants to States and local govern-  
 18 ments for the purpose of carrying out demonstration  
 19 projects to improve access to health and other services re-  
 20 garding seizures to encourage early detection and treat-  
 21 ment in children and others residing in medically under-  
 22 served areas.

23       (b) APPLICATION FOR GRANT.—The Secretary may  
 24 make a grant under subsection (a) only if the application  
 25 for the grant is submitted to the Secretary and the appli-

1 cation is in such form, is made in such matter, and con-  
 2 tains such agreements, assurances, and information as the  
 3 Secretary determines to be necessary to carry out this sec-  
 4 tion.

5 (c) AUTHORIZATION OF APPROPRIATIONS.—For the  
 6 purpose of carrying out this section, there are authorized  
 7 to be appropriated such sums as may be necessary for  
 8 each of the fiscal years 2000 through 2003.

9 **SEC. 273. DEFINITIONS.**

10 For purposes of this subtitle:

11 (1) The term “epilepsy” refers to a chronic and  
 12 serious neurological condition which produces exces-  
 13 sive electrical discharges in the brain causing recur-  
 14 ring seizures affecting all life activities. The Sec-  
 15 retary may revise the definition of such term as the  
 16 Secretary.

17 (2) The term “medically underserved” has the  
 18 meaning applicable under section 799B(6) of the  
 19 Public Health Service Act.

20 **Subtitle J—Asthma Treatment**  
 21 **Services for Children**

22 **SEC. 276. SHORT TITLE.**

23 This subtitle may be cited as the “Children’s Asthma  
 24 Relief Act of 1999”.

1 **SEC. 277. CHILDREN'S ASTHMA RELIEF.**

2 Title III of the Public Health Service Act, as amend-  
3 ed by section 252 of this Act, is amended by adding at  
4 the end the following:

5 "PART S—CHILDREN'S ASTHMA RELIEF

6 **"SEC. 399V. ASTHMA TREATMENT GRANTS PROGRAM.**

7 "(a) PURPOSES.—The purposes of this section are as  
8 follows:

9 "(1) To provide access to quality medical care  
10 for children who live in areas that have a high prev-  
11 alence of asthma and who lack access to medical  
12 care.

13 "(2) To provide on-site education to parents,  
14 children, health care providers, and medical teams to  
15 recognize the signs and symptoms of asthma, and to  
16 train them in the use of medications to prevent and  
17 treat asthma.

18 "(3) To decrease preventable trips to the emer-  
19 gency room by making medication available to indi-  
20 viduals who have not previously had access to treat-  
21 ment or education in the prevention of asthma.

22 "(4) To provide other services, such as smoking  
23 cessation programs, home modification, and other  
24 direct and support services that ameliorate condi-  
25 tions that exacerbate or induce asthma.

26 "(b) AUTHORITY TO MAKE GRANTS.—

1           “(1) IN GENERAL.—In addition to any other  
2       payments made under this Act or title V of the So-  
3       cial Security Act, the Secretary shall award grants  
4       to eligible entities to carry out the purposes of this  
5       section, including grants that are designed to de-  
6       velop and expand projects to—

7           “(A) provide comprehensive asthma serv-  
8       ices to children, including access to care and  
9       treatment for asthma in a community-based  
10      setting;

11          “(B) fully equip mobile health care clinics  
12      that provide preventive asthma care including  
13      diagnosis, physical examinations, pharma-  
14      cological therapy, skin testing, peak flow meter  
15      testing, and other asthma-related health care  
16      services;

17          “(C) conduct study validated asthma man-  
18      agement education programs for patients with  
19      asthma and their families, including patient  
20      education regarding asthma management, fam-  
21      ily education on asthma management, and the  
22      distribution of materials, including displays and  
23      videos, to reinforce concepts presented by med-  
24      ical teams; and

1 “(D) identify eligible children for the med-  
2 icaid program under title XIX of the Social Se-  
3 curity Act, the State Children’s Health Insur-  
4 ance Program under title XXI of such Act, or  
5 other children’s health programs.

6 “(2) AWARD OF GRANTS.—

7 “(A) APPLICATION.—

8 “(i) IN GENERAL.—An eligible entity  
9 shall submit an application to the Sec-  
10 retary for a grant under this section in  
11 such form and manner as the Secretary  
12 may require.

13 “(ii) REQUIRED INFORMATION.—An  
14 application submitted under this subpara-  
15 graph shall include a plan for the use of  
16 funds awarded under the grant and such  
17 other information as the Secretary may re-  
18 quire.

19 “(B) REQUIREMENT.—In awarding grants  
20 under this section, the Secretary shall give pref-  
21 erence to eligible entities that demonstrate that  
22 the activities to be carried out under this sec-  
23 tion shall be in localities within areas of known  
24 high prevalence of childhood asthma or high  
25 asthma-related mortality (relative to the aver-



1 age asthma incidence rates and associated mor-  
2 tality rates in the United States). Acceptable  
3 data sets to demonstrate a high prevalence of  
4 childhood asthma or high asthma-related mor-  
5 tality may include data from Federal, State, or  
6 local vital statistics, claims data under title XIX  
7 or XXI of the Social Security Act, other public  
8 health statistics or surveys, or other data that  
9 the Secretary, in consultation with the Director  
10 of the Centers for Disease Control and Preven-  
11 tion, deems appropriate.

12 “(3) DEFINITION OF ELIGIBLE ENTITY.—For  
13 purposes of this section, the term ‘eligible entity’  
14 means a State agency or other entity receiving funds  
15 under title V of the Social Security Act, a local com-  
16 munity, a nonprofit children’s hospital or founda-  
17 tion, or a nonprofit community-based organization.

18 “(c) COORDINATION WITH OTHER CHILDREN’S PRO-  
19 GRAMS.—An eligible entity shall identify in the plan sub-  
20 mitted as part of an application for a grant under this  
21 section how the entity will coordinate operations and ac-  
22 tivities under the grant with—

23 “(1) other programs operated in the State that  
24 serve children with asthma, including any such pro-

1       grams operated under titles V, XIX, or XXI of the  
2       Social Security Act; and

3       “(2) one or more of the following—

4               “(A) the child welfare and foster care and  
5       adoption assistance programs under parts B  
6       and E of title IV of such Act;

7               “(B) the head start program established  
8       under the Head Start Act (42 U.S.C. 9831 et  
9       seq.);

10              “(C) the program of assistance under the  
11       special supplemental nutrition program for  
12       women, infants and children (WIC) under sec-  
13       tion 17 of the Child Nutrition Act of 1966 (42  
14       U.S.C. 1786);

15              “(D) local public and private elementary or  
16       secondary schools; or

17              “(E) public housing agencies, as defined in  
18       section 3 of the United States Housing Act of  
19       1937 (42 U.S.C. 1437a).

20       “(d) EVALUATION.—An eligible entity that receives  
21       a grant under this section shall submit to the Secretary  
22       an evaluation of the operations and activities carried out  
23       under the grant that includes—

24              “(1) a description of the health status outcomes  
25       of children assisted under the grant;

1           “(2) an assessment of the utilization of asthma-  
2           related health care services as a result of activities  
3           carried out under the grant;

4           “(3) the collection, analysis, and reporting of  
5           asthma data according to guidelines prescribed by  
6           the Director of the Centers for Disease Control and  
7           Prevention; and

8           “(4) such other information as the Secretary  
9           may require.

10          “(e) APPLICABILITY OF CERTAIN PROVISIONS.—The  
11       following provisions of title V of the Social Security Act  
12       shall apply to a grant made under this section to the same  
13       extent and in the same manner as such provisions apply  
14       to allotments made under section 502(c) of such Act:

15               “(1) Section 504(b)(4) (relating to expenditures  
16               of funds as a condition of receipt of Federal funds).

17               “(2) Section 504(b)(6) (relating to prohibition  
18               on payments to excluded individuals and entities).

19               “(3) Section 506 (relating to reports and au-  
20               dits, but only to the extent determined by the Sec-  
21               retary to be appropriate for grants made under this  
22               section).

23               “(4) Section 508 (relating to nondiscrimina-  
24               tion).

1       “(f) AUTHORIZATION OF APPROPRIATIONS.—For the  
 2 purpose of carrying out this section, there are authorized  
 3 to be appropriated such sums as may be necessary for  
 4 each of the fiscal years 2000 through 2003.”.

5 **SEC. 278. INCORPORATION OF ASTHMA PREVENTION**  
 6 **TREATMENT AND SERVICES INTO STATE**  
 7 **CHILDREN’S HEALTH INSURANCE PRO-**  
 8 **GRAMS.**

9       (a) IN GENERAL.—The Secretary of Health and  
 10 Human Services (in this section referred to as the “Sec-  
 11 retary”) shall, in accordance with subsection (b), carry out  
 12 a program to encourage States to implement plans to  
 13 carry out activities to assist children with respect to asth-  
 14 ma in accordance with guidelines of the National Asthma  
 15 Education and Prevention Program (NAEPP) and the  
 16 National Heart, Lung and Blood Institute.

17       (b) RELATION TO CHILDREN’S HEALTH INSURANCE  
 18 PROGRAM.—

19           (1) IN GENERAL.—Subject to paragraph (2), if  
 20 a State child health plan under title XXI of the So-  
 21 cial Security Act (42 U.S.C. 1397aa et seq.) pro-  
 22 vides for activities described in subsection (a) to an  
 23 extent satisfactory to the Secretary, the Secretary  
 24 shall, with amounts appropriated under subsection

1 (c), make a grant to the State involved to assist the  
2 State in carrying out such activities.

3 (2) CRITERIA REGARDING ELIGIBILITY FOR  
4 GRANT; RULE OF CONSTRUCTION REGARDING AU-  
5 THORITY OF SECRETARY.—The Secretary shall pub-  
6 lish in the Federal Register criteria describing the  
7 circumstances in which the Secretary will consider a  
8 State plan to be satisfactory for purposes of para-  
9 graph (1), subject to the condition that this section  
10 may not be construed as modifying (or authorizing  
11 the Secretary to modify) any requirement or author-  
12 ity established in or under title XXI of the Social  
13 Security Act.

14 (3) REQUIREMENT OF MATCHING FUNDS.—

15 (A) IN GENERAL.—With respect to the  
16 costs of the activities to be carried out by a  
17 State pursuant to paragraph (1), the Secretary  
18 may make a grant under such paragraph only  
19 if the State agrees to make available (directly  
20 or through donations from public or private en-  
21 tities) non-Federal contributions toward such  
22 costs in an amount that is not less than 15 per-  
23 cent of the costs.

24 (B) DETERMINATION OF AMOUNT CON-  
25 TRIBUTED.—Non-Federal contributions re-

1           quired in subparagraph (A) may be in cash or  
2           in kind, fairly evaluated, including equipment or  
3           services. Amounts provided by the Federal Gov-  
4           ernment, or services assisted or subsidized to  
5           any significant extent by the Federal Govern-  
6           ment, may not be included in determining the  
7           amount of such non-Federal contributions.

8           (4) TECHNICAL ASSISTANCE.—With respect to  
9           State child health plans under title XXI of the So-  
10          cial Security Act (42 U.S.C. 1397aa et seq.), the  
11          Secretary, acting through the Director of the Cen-  
12          ters for Disease Control and Prevention, in consulta-  
13          tion with the heads of other Federal agencies in-  
14          volved in asthma treatment and prevention, shall  
15          make available to the States technical assistance in  
16          developing the provision of such plans that will pro-  
17          vide for activities pursuant to paragraph (1).

18          (c) FUNDING.—For the purpose of carrying out this  
19          section, there are authorized to be appropriated such sums  
20          as may be necessary for each of the fiscal years 2000  
21          through 2003.

1 **SEC. 279. PREVENTIVE HEALTH AND HEALTH SERVICES**  
2 **BLOCK GRANT; SYSTEMS FOR REDUCING**  
3 **ASTHMA AND ASTHMA-RELATED ILLNESSES**  
4 **THROUGH URBAN COCKROACH MANAGE-**  
5 **MENT.**

6 Section 1904(a)(1) of the Public Health Service Act  
7 (42 U.S.C. 300w-3(a)(1)) is amended—

8 (1) by redesignating subparagraphs (E) and  
9 (F) as subparagraphs (F) and (G), respectively;

10 (2) by adding a period at the end of subpara-  
11 graph (G) (as so redesignated);

12 (3) by inserting after subparagraph (D), the  
13 following:

14 “(E) The establishment, operation, and coordi-  
15 nation of effective and cost-efficient systems to re-  
16 duce the prevalence of asthma and asthma-related  
17 illnesses among urban populations, especially chil-  
18 dren, by reducing the level of exposure to cockroach  
19 allergen through the use of integrated pest manage-  
20 ment, as applied to cockroaches. Amounts expended  
21 for such systems may include the costs of structural  
22 rehabilitation of housing, public schools, and other  
23 public facilities to reduce cockroach infestation, the  
24 costs of building maintenance, and the costs of pro-  
25 grams to promote community participation in the  
26 carrying out at such sites of integrated pest manage-

1       ment, as applied to cockroaches. For purposes of  
 2       this subparagraph, the term ‘integrated pest man-  
 3       agement’ means an approach to the management of  
 4       pests in public facilities that combines biological,  
 5       cultural, physical, and chemical tools in a way that  
 6       minimizes economic, health, and environmental  
 7       risks.”;

8               (4) in subparagraph (F) (as so redesignated),  
 9       by striking “subparagraphs (A) through (D)” and  
 10       inserting “subparagraphs (A) through (E)”; and

11              (5) in subparagraph (G) (as so redesignated),  
 12       by striking “subparagraphs (A) through (E)” and  
 13       inserting “subparagraphs (A) through (F)”.

14   **SEC. 279A. COORDINATION OF FEDERAL ACTIVITIES TO AD-**  
 15                   **DRESS   ASTHMA-RELATED   HEALTH   CARE**  
 16                   **NEEDS.**

17       (a) IN GENERAL.—The Director of the National  
 18       Heart, Lung, and Blood Institute shall, through the Na-  
 19       tional Asthma Education Prevention Program Coordi-  
 20       nating Committee—

21              (1) identify all Federal programs that carry out  
 22       asthma-related activities;

23              (2) develop, in consultation with appropriate  
 24       Federal agencies and professional and voluntary



1 health organizations, a Federal plan for responding  
2 to asthma; and

3 (3) not later than 12 months after the date of  
4 enactment of this Act, submit recommendations to  
5 Congress on ways to strengthen and improve the co-  
6 ordination of asthma-related activities of the Federal  
7 Government.

8 (b) REPRESENTATION OF THE DEPARTMENT OF  
9 HOUSING AND URBAN DEVELOPMENT.—A representative  
10 of the Department of Housing and Urban Development  
11 shall be included on the National Asthma Education Pre-  
12 vention Program Coordinating Committee for the purpose  
13 of performing the tasks described in subsection (a).

14 (c) AUTHORIZATION OF APPROPRIATIONS.—For the  
15 purpose of carrying out this section, there are authorized  
16 to be appropriated such sums as may be necessary for  
17 each of the fiscal years 2000 through 2003.

18 **SEC. 279B. COMPILATION OF DATA BY THE CENTERS FOR**  
19 **DISEASE CONTROL AND PREVENTION.**

20 (a) IN GENERAL.—The Director of the Centers for  
21 Disease Control and Prevention, in consultation with the  
22 National Asthma Education Prevention Program Coordi-  
23 nating Committee, shall—

24 (1) conduct local asthma surveillance activities  
25 to collect data on the prevalence and severity of

1       asthma and the quality of asthma management,  
2       including—

3               (A) telephone surveys to collect sample  
4               household data on the local burden of asthma;  
5               and

6               (B) health care facility specific surveillance  
7               to collect asthma data on the prevalence and se-  
8               verity of asthma, and on the quality of asthma  
9               care; and

10       (2) compile and annually publish data on—

11               (A) the prevalence of children suffering  
12               from asthma in each State; and

13               (B) the childhood mortality rate associated  
14               with asthma nationally and in each State.

15       (b) COLLABORATIVE EFFORTS.—The activities de-  
16       scribed in subsection (a)(1) may be conducted in collabo-  
17       ration with eligible entities awarded a grant under section  
18       399V of the Public Health Service Act (as added by sec-  
19       tion 277 of this Act).

## 20       **Subtitle K—Juvenile Arthritis and** 21       **Related Conditions**

### 22       **SEC. 281. RESEARCH ON JUVENILE ARTHRITIS AND RE-** 23       **LATED CONDITIONS.**

24       (a) ESTABLISHMENT.—The Directors of the National  
25       Institute of Arthritis and Musculoskeletal and Skin Dis-

1 eases and the National Institute of Allergy and Infectious  
2 Diseases shall expand and intensify the programs of such  
3 Institutes with respect to research and related activities  
4 concerning juvenile arthritis and related conditions.

5 (b) COORDINATION.—The Directors referred to in  
6 subsection (a) shall jointly coordinate the programs re-  
7 ferred to in such subsection and consult with the Arthritis  
8 and Musculoskeletal Diseases Interagency Coordinating  
9 Committee.

10 (c) INFORMATION RESOURCE CENTER.—

11 (1) IN GENERAL.— In order to assist in car-  
12 rying out the purpose described in subsection (a),  
13 the Director of the National Institutes of Health  
14 shall provide for the establishment of an information  
15 resource center on arthritis and related conditions,  
16 including juvenile arthritis, to facilitate and enhance  
17 knowledge and understanding on the part of pa-  
18 tients, health professionals, and the public through  
19 the effective dissemination of information.

20 (2) ESTABLISHMENT THROUGH GRANT OR CON-  
21 TRACT.—For the purpose of carrying out paragraph  
22 (1), the Director of the National Institutes of Health  
23 shall enter into a grant, cooperative agreement, or  
24 contract with a national, nonprofit private entity in-  
25 volved in activities regarding the prevention and con-

1        trol of arthritis and related conditions through the  
2        National Arthritis Action Plan.

3        (c) PEDIATRIC RHEUMATOLOGY.—The Secretary of  
4        Health and Human Services, acting through the Director  
5        of the National Institutes of Health and the Administrator  
6        of the Health Resources and Services Administration,  
7        shall develop a coordinated effort to ensure that a national  
8        infrastructure is in place to train and develop pediatric  
9        rheumatologists to address the health care services re-  
10       quirements of children with arthritis and related condi-  
11       tions.

12       (d) AUTHORIZATION OF APPROPRIATIONS.—For the  
13       purpose of carrying out this section, there are authorized  
14       to be appropriated such sums as may be necessary for  
15       each of the fiscal years 2000 through 2003.

16       **Subtitle L—Childhood Skeletal**  
17       **Malignancies**

18       **SEC. 286. PROGRAMS OF CENTERS FOR DISEASE CONTROL**  
19       **AND PREVENTION.**

20       (a) IN GENERAL.—The Secretary of Health and  
21       Human Services (in this section referred to as the “Sec-  
22       retary”), acting through the Director of the Centers for  
23       Disease Control and Prevention, shall study environmental  
24       and other risk factors for childhood skeletal cancers, and  
25       carry out projects to improve outcomes among children

1 with childhood skeletal cancers and resultant secondary  
2 conditions, including limb loss. Such projects shall be car-  
3 ried out by the Secretary directly and through awards of  
4 grants or contracts to public or nonprofit entities.

5 (b) CERTAIN ACTIVITIES.—Activities under sub-  
6 section (a) include—

7 (1) the expansion of current demographic data  
8 collection and population surveillance efforts to in-  
9 clude childhood skeletal cancers nationally;

10 (2) the development of a uniform reporting sys-  
11 tem under which treating physicians, hospitals, clin-  
12 ics, and states report the diagnosis of childhood skel-  
13 etal cancers, including relevant associated epidemio-  
14 logical data; and

15 (3) support for the National Limb Loss Infor-  
16 mation Center to address, in part, the primary and  
17 secondary needs of persons who experience childhood  
18 skeletal cancers in order to prevent or minimize the  
19 disabling nature of these cancers.

20 (c) COORDINATION OF ACTIVITIES.—The Secretary  
21 shall assure that activities under this section are coordi-  
22 nated as appropriate with other agencies of the Public  
23 Health Service that carry out activities focused on child-  
24 hood cancers and limb loss.

1 (d) DEFINITION.—For purposes of this section, the  
 2 term “childhood skeletal cancer” refers to any malignancy  
 3 originating in the connective tissue of a person before skel-  
 4 etal maturity including the appendicular and axial skel-  
 5 eton. The Secretary may revise the definition of such term  
 6 as determined necessary to carry out the intent of this  
 7 effort.

8 (e) AUTHORIZATION OF APPROPRIATIONS.—For the  
 9 purpose of carrying out this section, there are authorized  
 10 to be appropriated such sums as may be necessary for  
 11 each of the fiscal years 2000 through 2003.

12 **Subtitle M—Reducing Burden of**  
 13 **Diabetes Among Children and**  
 14 **Youth**

15 **SEC. 291. PROGRAMS REGARDING DIABETES IN CHILDREN**  
 16 **AND YOUTH.**

17 (a) NATIONAL REGISTRY ON JUVENILE DIABETES.—  
 18 The Secretary of Health and Human Services (in this sec-  
 19 tion referred to as the “Secretary”), acting through the  
 20 Director of the Centers for Disease Control and Preven-  
 21 tion, shall develop a system to collect data on juvenile dia-  
 22 betes, including with respect to incidence and prevalence,  
 23 and shall establish a national database for such data.

24 (b) LONG-TERM EPIDEMIOLOGY STUDIES ON JUVE-  
 25 NILE DIABETES.—

1           (1) IN GENERAL.—The Secretary, acting  
2           through the Director of the National Institutes of  
3           Health, shall conduct or support long-term epidemi-  
4           ology studies in which individuals with type 1, or ju-  
5           venile, diabetes are followed for 10 years or more.  
6           Such studies shall, in order to provide a valuable re-  
7           source for the purposes specified in paragraph (2),  
8           provide for complete characterization of disease  
9           manifestations, appropriate medical history, eluci-  
10          dation of environmental factors, delineation of com-  
11          plications, results of usual medical treatment and a  
12          variety of other potential valuable (such as samples  
13          of blood).

14          (2) PURPOSES.—The purposes referred to in  
15          paragraph (1) with respect to type 1 diabetes are  
16          the following:

17                (A) Delineation of potential environmental  
18                triggers thought precipitating or causing type 1  
19                diabetes.

20                (B) Delineation of those clinical character-  
21                istics or lab measures associated with complica-  
22                tions of the disease.

23                (C) Potential study population to enter  
24                into clinical trials for prevention and treatment,  
25                as well as genetic studies.

1       (c) TYPE 2 DIABETES IN YOUTH.—The Secretary,  
2 acting through the Director of the Centers for Disease  
3 Control and Prevention, shall implement a national public  
4 health effort to address type 2 diabetes in youth,  
5 including—

6           (1) enhancing surveillance systems and expand-  
7 ing research to better assess the prevalence of type  
8 2 diabetes in youth and determine the extent to  
9 which type 2 diabetes is incorrectly diagnosed as  
10 type 1 diabetes among children; and

11          (2) assisting States in establishing coordinated  
12 school health programs and physical activity and nu-  
13 trition demonstration programs to control weight  
14 and increase physical activity among youth.

15       (d) CLINICAL TRIAL INFRASTRUCTURE/INNOVATIVE  
16 TREATMENTS FOR JUVENILE DIABETES.—The Secretary,  
17 acting through the Director of the National Institutes of  
18 Health, shall support regional clinical centers for the cure  
19 of juvenile diabetes and shall through such centers provide  
20 for—

21           (1) well-characterized population of children ap-  
22 propriate for study;

23           (2) well-trained clinical scientists able to con-  
24 duct such trials;



1           (3) appropriate clinical settings able to house  
2       such studies; and

3           (4) appropriate statistical capability, data, safe-  
4       ty and other monitoring capacity.

5       (e) DEVELOPMENT OF VACCINE.—The Secretary,  
6       acting through the appropriate agencies of the Public  
7       Health Service, shall provide for a national effort to de-  
8       velop a vaccine for type 1 diabetes. Such effort shall pro-  
9       vide for a combination of increased efforts in research and  
10      development of candidate vaccines, coupled with appro-  
11      priate ability to conduct large clinical trials in children.

12      (f) AUTHORIZATION OF APPROPRIATIONS.—For the  
13      purpose of carrying out this section, there are authorized  
14      to be appropriated such sums as may be necessary for  
15      each of the fiscal years 2000 through 2003.

## 16                   **Subtitle N—Miscellaneous** 17                   **Provisions**

### 18   **SEC. 296. REPORT REGARDING RESEARCH ON RARE DIS-** 19                   **EASES IN CHILDREN.**

20           Not later than 180 days after the date of the enact-  
21      ment of this Act, the Director of the National Institutes  
22      of Health shall submit to the Congress a report on—

23           (1) the activities that, during fiscal year 1999,  
24      were conducted and supported by such Institutes

1       with respect to rare diseases in children, including  
2       Friedreich's ataxia; and  
3               (2) the activities that are planned to be con-  
4       ducted and supported by such Institutes with respect  
5       to such diseases during the fiscal years 2000  
6       through 2003.

○